



VALUE+ EPF
Autumn Regional Advocacy Seminar for Patient Leaders

The politics of health policy making at EU level
and meaningful patient involvement through VALUE +

Sofia, Bulgaria
September 18-19 2009

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Introduction

On 18-19 September 2008 the European Patients' Forum (EPF) held its annual autumn advocacy seminar for patients' leaders. It was the second seminar linked to the project VALUE+, a project on patient involvement co-funded by the European Commission that EPF is coordinating. The first one had taken place in Lithuania on November 2008.

It was also the second seminar having a "regional" approach; the delegates represented patient organisations from Bulgaria, Romania, Slovenia, Hungary, Greece and Cyprus. Approximately 50 patients' leaders attended the event.

The purpose of the seminar was to build knowledge and know-how on working at the European Union level through and with EPF, discuss findings from the VALUE + project as well as its deliverables.

The first part of the seminar was dedicated to an introduction to EU policy-making and decision-making processes. We discussed the role of various EU institutions and how patients' organisations can interact with them. The speeches made by representatives from the European Parliament and the European Commission offered useful insights. There was also a presentation on how the Council of Ministers functions, and the national political perspective brought by the intervention of a national umbrella patient organisation.

The other main focus was VALUE+, which was able to share the final findings of the assessment on patient involvement in health-related projects supported by the European Commission.

This report outlines the seminar conclusions and recommendations and includes a summary of the presentations in plenary and of the workshop sessions. The complete presentations are available on the EPF web site www.eu-patient.eu.

EPF would like to thank the Bulgarian Confederation "Health Protection" (KZZ) for their support in organising the seminar, the Medtronic Foundation for their generous financial support in the form of an unrestricted grant for the seminar and the speakers, and participants for their engagement and energy in making this Regional Seminar a real success.

Summary of Presentations

Welcome Speeches

- *Ms. Veska Sabeva, Board Member - Confederation "Health Protection" of Bulgaria*
- *Mr. Luc Giraud - The Medtronic Foundation*
- *Mr. Mike O'Donovan, Board Member - European Patients' Forum*

Key points:

- Emphasis on ensuring that patients have access to advanced and modern healthcare services; the voice of patients is important and must be heard
- Networking, sharing good practices and expertise, and building credibility and efficient partnerships
- Need for a united patient movement at the European level to have a strong voice
- Importance for EPF to work as closely as possible with patient groups from different regions of the EU to understand their needs, and how they can help to shape the policy work of EPF.

Presentation of EPF

Ms. Nicola Bedlington, European Patients' Forum

Key points:

- Membership: EPF is an umbrella organisation of currently 39 disease-specific European patients' organisations and national platforms
- Vision and Mission: high quality, patient-centred, equitable health care in Europe
- EPF Strategic Plan for five years and EPF key strategic goals: equal access for patients, patient involvement, patients' perspective, sustainable patient organisations and patient unity
- Specific objectives for 2010: build capacity of EPF, strengthen EPF's policy impact and put patients at the centre of policies that concern them, build the patients' evidence base, extend membership, build powerful communications and partnerships, diversify the funding base
- The EPF Manifesto "150 Million Reasons to Act": launched in September 2008 at the European Parliament, it has been at the core of some national campaigns – a tool to set the agenda
- Working towards enhanced outreach to patient networks at national level.

The Role of the European Parliament

Ms. Antonia Parvanova, Bulgarian Member of the European Parliament

Key points:

- Patient organisations' feed-back is very important in MEPs' work; patient organisations need to be more pro-active in approaching the MEPs
- Intensive legislative work is going on in the European Parliament with several policy dossiers under discussion: Declaration on Mental Health, Report on Rare Diseases, Directive on patients' rights in cross-border health-care, Pharmaceutical package legislation, etc
- With the Lisbon Treaty endorsed, the European Parliament will be more powerful and MEPs need a high quality patients' representation like the work undertaken by EPF.
- Emphasis on a stronger cooperation between decision-makers, patients and health professionals
- There are unacceptable inequalities in terms of patients' access to healthcare and effective European and national legislation is needed to tackle these, despite the budget constraints
- Political compromise is not easy to find, but we need to commit to patients' legitimate rights.

Working with the European Council

Ms. Roxana Radulescu and Ms. Nicola Bedlington, EPF

Key points:

- The Council of Ministers or Council is the EU main decision-making body, representing 27 Member States and meeting in nine configurations. The configuration dealing with health is "Employment, Social Policy, Health and Consumer Affairs (EPSCO) "
- Decision-making procedure related to public health and medicines: acts adopted by "codecision procedure"; two readings plus conciliation; qualified majority needed; subsidiarity of Member States in the area of health is acknowledged
- Presidency of the Council is based on a rotating system: a presidency lasts for six months but there is a programme for 18 months that is prepared with the previous and future presidencies
- Role of presidency: administrative and political role (organises work of the Council and deals with political situations, mediates in Council). The presidency is neutral
- With regard to patient organisations' involvement in setting the EU presidencies' priorities: NGOs need to start contacting the health ministries and national governments at a very early stage, at least one year before the presidency

- Recommendation to suggest concrete priorities to the Government; these priorities must be topics in which Member States can bring an added value at the European level
- The primary focus of the current Swedish presidency is on the economy, climate change and institutional changes.

Patien' Organisations Working in National Coalitions

Mr. Cezar Irimia, Coalition of Romanian Chronic Patients Organisations

Key points:

- For the first time most major NGOs representing patients' interests are joined together under the COPAC umbrella aligning their actions in a joint approach
- COPAC was recognized by the Ministry of Health, the National Insurance House and the Romanian College of Physicians as a common voice of patient organisations
- Examples of initiatives undertaken: advocating increase of health care spending to 6% of GDP; representation in the Expert Committee of the National Healthcare Fund; media campaign against co-payment (by patients) programme within the health care system, roundtables in cooperation with the National Association for Patients Rights in order to increase the knowledge of patients rights
- Patients' voice is still at the beginning of a structural entity formation, but its acceptance is rapidly growing especially among healthcare professionals – it is more difficult with public institutions.

Overview of Evolving Patient Involvement in EU Policies and Actions - the European Health Strategy and "Europe for Patients" Campaign

Ms. Rostislava Dimitrova, European Commission Directorate General for Health and Consumers

Key points:

- In respect to the principle of subsidiarity in relation to health, the Commission's role is to support cooperation between the Member States and reinforce their action
- Objectives of the EU Health Strategy "Together for Health" 2008-2013: 1) Foster good health in ageing Europe; 2) Protect citizens from health threats; 3) Support dynamic health systems
- Some of the major health challenges: growing health gaps; migration & cross border health care; ageing population; lifestyle related diseases; new technology and innovation; citizens (including patients) want more control

- The purpose of the “Europe for Patients” campaign (http://ec.europa.eu/health-eu/europe_for_patients/index_en.htm) is to inform what is done to improve healthcare for all in Europe and to encourage sharing of information
- Main initiatives of the “Europe for Patients” campaign:
 - Directive on the application of patients' rights in cross-border healthcare
 - Commission Communication and Council Recommendation on a European action in the field of rare diseases
 - Green paper on the European Workforce for Health
 - Commission Communication and Council Recommendation on patient safety
 - Proposal for a directive setting standards of quality and safety of human organs intended for transplantation and others
- Suggestions for patients’ organisations on how to get involved in the EU policy and legislation process:
 - Become a member of a European umbrella organisation, which represents the patients’ perspective
 - Participate in the Open Forum, European Health Policy Forum, Stakeholders Forum etc
 - Send a response to Commission Open consultations on policy and legislative initiatives
 - Participate in Commission Working Groups, Joint Actions with MS and stakeholders
 - Take part in EU policy campaigns
 - Submit projects to the Public Health Programme.

The Health Policy Landscape from the Perspective of Patients

Ms. Roxana Radulescu, European Patients’ Forum

Key points:

- EPF’s work focuses on monitoring and analysing EU policies relevant for patients; alerting patients’ organisations about new EU policy developments; providing a strong patients’ voice and promoting patients’ organisations’ views, in accordance with EPF’s vision of high quality, patient-centred and equitable healthcare in Europe
- An EU Recommendation on Patient Safety & Health Care Associated Infections (adopted in June 2009) stimulated the debate on quality of health care – a Reflection Paper on Quality of Health Care is under preparation
- EPF responded to the consultation on the draft Directive on Cross-Border Healthcare based on values of quality, safety, equity and patient involvement
- EPF gave specific policy input on the EU Legislation package on information to patients, pharmacovigilance and counterfeiting.

- In the field of eHealth: Member States are called to develop action plans – the acts currently available are a EU Recommendation on interoperability of health systems and a EU Communication on telemedicine
- EPF's Manifesto '150 Million Reasons to Act' is a campaign calling for equal and timely access of effective diagnosis, treatment and support; better information and resources for patients and a strong patients' voice.

"Promoting Patients' Involvement in EU Supported Health-related Projects – Value+"

Ms. Liuska Sanna, European Patients' Forum

Key points:

- The project is funded by the Public Health Programme for a duration of two years and is coordinated by EPF in cooperation with a consortium of partners
- Purpose of project: to exchange information, experiences and good practices among key stakeholders in relation to the meaningful involvement of patient organisations in EU supported health projects at EU and national level
- The focus of Value+ is to assess patients' involvement in EU supported health-related projects to identify barriers and success factors
- The methodology used consists of a literature review, a questionnaire survey, focus groups and interviews
- A number of tools to help different stakeholders realise meaningful patient involvement are being produced: Value+ model of meaningful patient involvement; a toolkit for patient organisations; a handbook for project promoters and coordinators from different types of organisations; a set of policy recommendations.

VALUE+ Findings on Patient Involvement in EU Supported Health Related Projects

Ms. Liuska Sanna, European Patients' Forum

Key points:

- Focus: assessment of projects implemented in the period 1998-2008 financed by a number of EC programmes
- Sources of information: literature review, questionnaires, focus groups with patients and patients' representatives; interviews; workshop with project coordinators and patients /representatives
- According to the literature review there are three main levels of involvement: advisory status; institutionalised participation and participation in health related policy making

- With regard to projects assessed, patients and patient organisations were involved in most of them; however there is a low to medium degree of involvement in key aspects like development of project concept and management and coordination of activities
- Involvement of patients/patient organisations is seen as a benefit for addressing the right issues; validating good practices; empowering patients and achieving objectives.
- Barriers to patient involvement: lack of legislation and policies; poor commitment; lack of mechanisms and tools; scarce resources; communication and attitudes
- Factors being recognized as supporting involvement are financial, structural and institutional support; resources and training; acknowledgement of patients as experts and equal partners; appropriate communication
- In conclusion, patient organisations struggle in leading and/or being involved in European projects - meaningful patient involvement currently is not an objective in itself but it must become one - Value+ tools and resources can continue bridging some gaps.

Summary of Workshop Sessions

WORKSHOP 1: Getting Involved in a Consultation Process at the EU level:

Moderator: Ms. Nicola Bedlington, European Patients' Forum

Rapporteur: Ms. Kathi Apostolidis - Society of Volunteers Against Cancer, Greece

The EU Institutions consult health stakeholders, including patients on EU health policy instruments at various stages of the decision-making process. There are a number of different ways that national patient groups can be involved actively in this work, providing their viewpoints and experience. The workshop looked at why this is important; what are some of the 'pressure points' where national groups can engage effectively and what are the specific needs of patient groups to be able to play this role effectively.

Key points:

- Lack of information on national & EU policy issues
- Difficulty in using communications from EPF and other European umbrella organisations due to language and educational barriers
- EU issues or national policy not key activity for many patient organisations
- Inequality of human and knowledge resources/capacity to deal with policy matters among organisations of the same country or of the same disease
- Lack in several countries of powerful national umbrella organisations per specific diseases
- Antagonism between organisations representing specific diseases is a common characteristic in Southern Eastern Europe.

Recommendations:

The following recommendations were addressed in particular to EPF:

- Improve the recognition of the role of patients' organisations by the EU and national policy makers
- Examine the possibility to offer more frequently national/regional seminars/workshops on capacity building for handling EU or national policy issues
- Research good practices in policy advocacy and circulate same among EPF members
- Assist national organisations, willing and capable of undertaking policy advocacy, to build the necessary capacity
- Facilitate communication channels among patients, MEPs and key EU officials
- Strengthen the think-tank role of EPF on all issues concerning patients – for instance development of position papers to serve as a starting point for patient organisations.

WORKSHOP 2: Working with Members of the European Parliament

Moderator: Ms. Roxana Radulescu, European Patients' Forum

Rapporteur: Ms. Loredana Tascau - Romanian League for Mental Health

The 736 Members of the European Parliament are there to represent us, the citizens. They play an active role in influencing legislation which has an impact on our daily lives (e.g. cross-border health care, patient safety, medical devices, information to patients, combating counterfeit drugs, rare disease, research, labeling and packaging, etc). Participants to this workshop explored ways of working with the European Parliament; the most effective approaches; the challenges and the ways in which patient organisations can best make their voice heard.

Key points:

- For national patient organisations the MEPs of their own country should be the most accessible – the role and importance of MEPs assistants should not be underestimated with regard to reaching MEPs and getting your messages through
- It is important to get as much information as possible about the MEPs in order to address issues (biographies, background, concerns etc.)
- Taking timely action in advance is crucial, if a political or legal text is already at the Parliament or Council it might be too late to influence changes to the text
- Asking MEPs to lobby other MEPs can be a successful strategy.

Recommendations:

- Patient organisations should prepare their positions based on sound evidence and arguments – facts and figures should be researched
- When sending a letter or a position paper to MEPs, this will have more strength if supported by other organisations and stakeholders
- MEPs are very busy. Patient organisations should deliver their messages in a very clear and concise way.

WORKSHOP 3: Working with Different Media to Get your Message Across

Moderator: Mr. Derek Moloughney, consultant

Rapporteur: Ioanna Tsokanari, Greek Society of Alzheimer Disease and Related Disorders

Working with the media is an important aspect of communication work to make an organisation and its activities better known. The workshop addressed the following:

- How to establish coherence between the messages you wish to send and the Press
- Emphasise the importance of verbal and non-verbal communication skills when passing key messages

- How to define key messages and create positive images
- Understanding the needs and restraints of the journalist and what is behind their questions
- Showing how your objectives can coincide with the journalists' objectives
- The techniques for handling Written, T.V, Radio and Telephone Interviews.

Key points:

- Media looks for fast, accurate and concise information – the transmission of emotion is an important feature for delivering opinions and messages
- It is important to be clear about the objective of the communication to/with media whether that be through an interview, a press release or other means
- The experience of many representatives of patients organisations is that the interviews rarely reflect what they have actually said – as a result there is certain skepticism towards journalists
- It should not be taken for granted that journalists know about you, your organisation and the work it does.

Recommendations:

- A good definition of the message is crucial for a successful communication – key elements: identification of the target audiences; definition of the goal and clarity of the message
- In interviews it is important to understand that it is your interview and not the journalists' - one or two key messages should be prepared in advance and reiterated throughout the interview
- Key aspects for a good communicator are: body language, tone of voice, eye contact with audience, self confidence
- It is important to verify whether the message has been received correctly.

WORKSHOP 4: Meaningful Patient Involvement: Value+ Concept and Tools

Moderator: Ms Elizabeth Winder, European Network of (EX-) Users and Survivors of Psychiatry

Rapporteur: Ms Barbra Moskric, DAM Society (Society for Individuals Suffering from Depression and Anxiety Disorders), Slovenia

In this workshop participants looked at 'meaningful patient involvement', that is, patient involvement which is valued, and leads to project results which could not have been achieved without patient involvement. We looked at the model developed by Value+ for patient organisations, and the indicators of good practice which help build meaningful patient involvement. Has Value+ got it right? What must governments, public authorities,

health professionals, patients and citizens, and EPF do to make meaningful patient involvement a reality?

Key points:

- Communication between patient organisations and ordinary patients can be a very empowering factor for involvement
- Health literacy of patients has to be enhanced to enable them to get meaningfully involved in making decisions on their health—health literacy means not only knowledge on health issues but also the skills to apply that knowledge
- Social stigma prevents many patients from undertaking an active role
- Political variability has an impact on the work of patient organisations especially in terms of policy and resources.

Recommendations:

- Patients and patient organisations need to ally and set up organised pressure mechanism and actions on politicians – cooperation with health professionals should be sought
- Building communication channels with other patient organisations, policy makers and health stakeholders is fundamental for meaningful involvement
- Legislation establishing that patient organisations have to be involved in health related bodies and debates should be established.

WORKSHOP 5: Lobbying for Patient Involvement: Development of Policy Recommendations

Moderator: Ms. Liuska Sanna, European Patients' Forum

Rapporteur: Mr. Stanimir Hasurdjiev, National Association of People with Hepatitis (Bulgaria)

One of the expected outcomes of Value+ is a set of policy recommendations targeting the European Institutions and Member States aiming at enhancing political commitment and action towards meaningful patient involvement. This workshop looked into the main challenges to patient involvement identified by Value+ and participants had the opportunity to contribute to the formulation of these policy recommendations.

Key points:

- There is no European instrument highlighting patient involvement as a right and key issue – we need more pressure from the EU to Member States

- Specific political situations at national level make it very difficult for patient organisations to engage
- Access to resources: more financial resources are needed – mechanisms to access them have to be transparent and accessible: information, procedures, etc.
- Patient organisations need to better cooperate – working in coalitions is crucial
- Representativeness and professionalism of patient organisations is an important factor for patient involvement.

Recommendations:

- Political level:
 - EC should draft a Directive or other policy instrument on patients' rights and involvement in Member States
 - EC should set a mechanism and guidelines to ensure patient representation in health committees/bodies, decision-making processes (local, national, European)
- Resources and Capacity:
 - EC should adapt its grant system to allow patient organisations with a small capacity to access them - Simplification of procedures for accessing funds is needed (national and European context) and the co-financing should be waived for patient organisations
 - A minimal financing for patient organisations should be guaranteed in all MS
 - It is important to build the capacity of patient organisations and of the institutions administering EU funds at national level
 - Patient organisations should be involved in Health Technology Assessment; in developing standards for Quality of Care and accreditation of health care services and in redressing mechanisms for patients who have suffered injuries following care.

WORKSHOP 6: Patient Involvement in Research

Moderator: Ms. Jasna Russo, European Network of (EX-) Users and Survivors of Psychiatry

Rapporteur: Mr. Milan Hosta, Asthma and Sport Organisation Slovenia

This workshop explored the possibilities of patients' involvement in research beyond their traditional roles of research subjects. The focus was on experiential knowledge of persons living with a range of conditions as opposed to the academic or scientific knowledge. Different forms in which 'experts by experience' can contribute to creation of the research agenda, to developing research questions and methodology or to interpretation of the outcomes were presented. Exchanging their experiences and opinions the workshop participants had the opportunity to come up with suggestions for some key principles of patients' involvement in research.

Key points:

- Patient involvement in research is not about patients as research subjects, but about involvement of patients in the research process itself
- It is important to acknowledge the notion of experiential (first-hand) knowledge that patients can bring, its uniqueness and the essential role that it can take in the research process
- Patient involvement improves research, enables production of better quality knowledge and is crucial for creating science that comes closer to patient realities and responds better to their needs
- Hierarchical thinking and the dominance of medical knowledge prevent patients and their organisations from contributing to knowledge production on equal terms
- The topic of quality of life and not only symptom reduction is what patients bring to the research agenda. This topic is becoming more and more important which means that there will be an increasing role for patients.

Recommendations:

- Patient involvement should be included in legislation on research
- Patient involvement needs to be integrated from the beginning until the end of research projects
- Research funders are in a powerful position to improve patient involvement in research. Instead of requiring patient involvement only at the stage of project application they should demand to see its impact throughout the project. The topic of patient involvement should also be included in the project evaluation
- Patient involvement in research is not only about patients physically entering academia. It is about them bringing different values and different methodologies. Mechanisms to include patient perspectives are needed.

The views of Seminar Participants

Reflections from participants with regard to the seminar achieving the objective of building knowledge and sharing information and experience:

“I learned that as a single country it is more difficult to influence the health policy at EU level and it is better that all the patients speak with one voice”. (Romania)

“Through the workshops I had the opportunity to share and exchange ideas with other colleagues. I have also been helped by the plenary discussions regarding the actions we could launch”. (Greece)

“I was really glad to discover the strength of EPF. I think it gives more confidence to the patient associations to achieve their goals”. (Hungary)

“It worked on very common problems reflecting everyday situations and giving practical advice”. (Slovenia)

“It made clear how the EU is organised and how messages might go through and at what level we (patients) can interact”. (Hungary)

“It was very important for the organisations from the countries from the Eastern part of the EU to understand the importance of health policy”. (Romania).

EPF will organize its next regional advocacy seminar in Hungary in October 2010. The programme will put a particular emphasis on young people and their interaction with the health care environment.

About the European Patients' Forum (EPF)

The European Patients' Forum:

- Was set up in 2003 to become the strong and united collective patients' voice at European level and to put patients at the centre of EU healthcare policy and programmes
- Adopts a holistic interpretation of healthcare, to include prevention, and the social, economic, environmental, cultural and psychological aspects of health
- Has both a proactive and reactive role by acting as a catalyst and consultative partner for positive change in EU healthcare systems and as a “watchdog”, closely monitoring EU policy and legislative initiatives
- Is a credible and professional partner for cooperation, dialogue and negotiation with a broad range of EU level health stakeholders
- Facilitates exchange of good practice and challenging of bad practice on patients' rights, equitable access to treatment and care, and health-related quality of life between patient organisations at European level and at Member State level
- Offers a resource for member organisations on EU healthcare intelligence, information dissemination, baseline patient-rights policy responses to the EU Institutions to enable them to focus on disease specific responses
- Is open to European patient organisations and national umbrella organisations that fulfil criteria relating to legitimacy, representation, democracy, accountability and transparency. EPF has currently 40 member organisations.

Our **vision** is to establish patient-centred, equitable healthcare throughout the European Union. In order to achieve this, EPF demonstrates the solidarity, power and unity needed for an effective EU patients' movement.

Our **core values** emphasise a patient-centred approach to healthcare, inclusiveness, non-discrimination, patient empowerment, consultation and independency and transparency.

For more information on the European Patients' Forum:

www.eu-patient.eu